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Nos. 96-110 and 95-1858
IN THE
SUPREME COURT OF THE UNITED STATES
October Term, 1996

State of Washington
v.
Glucksberg

Vacco
v.
Quill

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT
OF APPEALS FOR THE SECOND AND NINTH CIRCUITS

Brief for the *Amici Curiae*:
Gay Men's Health Crisis and
Lambda Legal Defense and Education Fund:
On Behalf of their Members with Terminal Illnesses;
and Five Prominent Americans with Disabilities:
Evan Davis, Hugh Gregory Gallagher, Barbara Swartz,
Michael Stein and Susan Webb
In Support of Respondents

Attorneys for Amici:
Andrew I. Batavia, *Counsel of Record*
Bryan R. Cleveland
Marina L. Fontani
Susan F. Douraux
McDermott, Will & Emery
201 S. Biscayne Boulevard
Suite 2200
Miami, Florida 33131
(305) 347-3300

Date:

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I. INTERESTS OF AMICI CURIAE¹

People with disabilities do not speak with one voice on whether individuals with terminal illnesses should be permitted to end their own suffering with the assistance of their physicians and to choose a death with dignity. While some members of the disability community have been extremely vocal in opposing the right to assisted suicide, the majority of individuals with disabilities, including the *Amici* filing this brief, believe that such a right exists – that it is entirely consistent with our Constitutional tradition and the hard-fought rights secured by the disability rights movement in this country.

Amici are individuals and organizations representing people with a broad array of disabilities who share the common belief that individuals with disabilities should have autonomy over the decisions that affect their lives. They believe that the fundamental right of self-determination must apply to all significant life decisions, including what is perhaps the most intimate and personal decision of all, whether to hasten impending death if their conditions become terminal and they are suffering intolerably.

The two *Amici* organizations represent people who have AIDS, some of whom are in the terminal phase of their illnesses. The Lambda Legal Defense and Education Fund is a national non-profit public interest legal organization working for the civil rights of people with HIV and AIDS. The Gay Men's Health Crisis is the oldest and largest not for profit AIDS organization providing services to people with AIDS and their loved ones, educating the public and advocating for fair and effective AIDS policies. These organizations contend that the state should not be allowed to prohibit their members from receiving the assistance of their physicians in ending their lives when they have decided that life is no longer bearable.

¹ Amici were granted consent to file this brief.

The individual *Amici* are leaders in the disability community or prominent individuals with disabilities. Evan Davis is a partner with a major national law firm who had polio at age five. Hugh Gallagher is one of the leading historians on disability in this country. Michael Stein is the former President of the National Disability Bar Association. Barbara Swartz is a professor who has kidney disease. Susan Webb is the director of an independent living center for people with disabilities and an elected member of a national disability rights organization. All have disabilities but not terminal illnesses, and believe that they should have the right to hasten their death should they ever become terminally ill. Their personal statements are attached as an appendix to this brief.

Amici believe that the Constitution guarantees people with terminal illnesses the right to end their lives in a manner that allows them to maintain personal dignity. The attempt of Petitioners and their *amici* to use disability to justify state deprivation of this fundamental right is deeply offensive to *Amici* and the thousands of people with disabilities they represent.

A. The Disability Rights Movement

The disability rights movement is a social movement with the goal of achieving independence and autonomy for people with disabilities in all aspects of their lives. Gerben DeJong, *Independent Living: From Social Movement to Analytic Paradigm*, 60 Arch. Physical Med. Rehab. 435 (1979).² Judy Heumann, one of the pioneers of the movement, co-founder of the World Institute on Disability and currently the Assistant Secretary for Special Education and Rehabilitation Services at the U.S.

² The terms "disability rights movement" and "independent living movement" are often used interchangeably by members of the disability community. Whether they are two separate social movements or two names for basically the same movement is a matter of debate. For purposes of this brief, the broader term "disability rights movement" is used to refer to both.

Department of Education, expressed the driving spirit of the movement best in an early policy report:

To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a "normal" body.

Susan Stoddard Pflueger, *Independent Living: Emerging Issues in Rehabilitation*, foreword ii (December, 1977) (unpublished report on file with the Institute for Research Utilization).

Similarly, Edward V. Roberts, one of the founding fathers of the movement, made the following observation:

I believe that the basic premise of the ... movement is that everyone has potential to live more independently. Our experience shows that even the most severely and profoundly disabled individual can be independent — they may need all kinds of help — But that they can be in control of their lives.

Id. at 1 (emphasis added).

Over time, the movement has been successful in altering the general belief in our society that people with disabilities are invariably vulnerable, exploitable, and incapable of making decisions that fundamentally affect their lives. Until recently, however, most people with disabilities accepted the predominant paternalism concerning disability and the control of their lives by other people, often to their detriment. It was only after three decades of political struggle, with the bipartisan enactment of The Americans with Disabilities Act of 1990 (the ADA)³ that our nation developed a consensus that competent adults with disabilities

can and should exercise control of their lives in the mainstream of our society.⁴

Among the rights that the movement has secured for people with disabilities are the right to live in the community, as opposed to in isolated, degrading and disempowering institutions, *Youngberg v. Romeo*, 457 U.S. 307 (1982); the right to be free of involuntary sterilization, *Relf v. Weinberger*, 372 F. Supp. 1196 (D.C.D.C. 1974), the right to raise a child, *In re Marriage of Carney*, 598 P.2d 36 (Cal. 1979); the right to have access to public streets, public transportation, schools, public services, privately owned places of public accommodation and places of employment, 42 U.S.C. §§ 12111-12181; and the right to a free and appropriate education, 20 U.S.C. § 1400 *et seq.* (1991).⁵

Entirely consistent with these rights is the right to control one's death when it is imminent — arguably the most fundamental right of all.

B. The Views of People with Disabilities

According to a major public opinion poll, 66 percent of people with disabilities support the right to assisted suicide, as compared with 70 percent of the general population. Louis Harris and Associates, Harris Poll no. 9, Table 105 (1995). This result is corroborated by a recent study which found that 63 percent of people with AIDS support this right, and 55 percent actually have considered this option for themselves. William

⁴ See generally, Jane West, ed., THE AMERICANS WITH DISABILITIES ACT: FROM POLICY TO PRACTICE (1991); Jane West, ed., IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT (1996); Mark Nagler, PERSPECTIVES ON DISABILITY (2nd ed. 1993); Lawrence O. Gostin & Henry A. Beyer, eds., IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT: RIGHTS AND RESPONSIBILITIES OF ALL AMERICANS (1993).

³ The Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq. (1990).

⁵ The Individuals with Disabilities Education Act (IDEA).

Breitbart, et al., *Interest in Physician-assisted Suicide Among Ambulatory HIV-Infected Patients*, 153 Am. J. Psychiatry 238 (1996). Another study found that 90 percent of people with AIDS support the right. Brett Tindall et al., *Attitudes to Euthanasia and Assisted Suicide in a Group of Homosexual Men with Advanced HIV Disease*, 6 J. Acquir. Immune. Defic. Syndr. 1069 (1993).

While resolution of this issue by a poll of those most affected would quickly end criminalization of assisted suicide, constitutional issues are not rightly settled by popular vote. The personal and religious views of those who support either side of this national debate are immaterial to the question of whether patients who are terminally ill have a constitutional right to receive such assistance. However, the experiences and treatment realities of those who have lived with disabilities, including cancer and AIDS, are relevant to the Court's analysis. These experiences provide an explanation of why a decision, and request for assistance in accelerating death, is a legitimate treatment option which merits Fourteenth Amendment protection.

The experiences of those involved in the treatment of AIDS are particularly illustrative. Since the beginning of the AIDS epidemic in the early 1980s, people with AIDS and their advocates and service providers have been committed to ensuring that an individual with AIDS has as much autonomy in his or her life as possible. Many living with this disease have been involved decision makers in each stage of their treatment. In striving to maintain control over their lives as their physical conditions deteriorate, they have made increasing use of legal planning documents such as health care proxies and powers of attorney to maintain control of their final days. The right to end their lives with the assistance of their physicians is a natural extension of their efforts to maintain autonomy. The state's intrusion, effectively forcing a person to continue living against his or her will, destroys the autonomy that has been central to the struggles of people with disabilities.

Based on their experiences, it is clear that people with disabilities, like the public at large, believe that the state should

not be allowed to interfere with a terminally ill individual's personal decision of how and when to die. This important fact has been obscured by the vocal minority of those disability leaders who adamantly oppose recognition of the right to assisted suicide. Given the above statistics and the hard-fought battle for people with disabilities to win their autonomy, it is anomalous that some, purporting to represent the interests of people with disabilities, are advocating in favor of the state's right to interfere with the individual's autonomy.

In essence, those disability rights advocates opposing the right to assisted suicide appear to be saying that the individual with a disability should have control over every decision in his or her life, except for the decision of whether to live in the face of a terminal illness. This blatant contradiction is glaring and unacceptable to a substantial majority of people with disabilities.

C. The Interests of People with Disabilities

The interests of *Amici* are similar to the interests of millions of people with disabilities throughout this country. Although the personal circumstances of people with disabilities vary substantially, they share a common interest in maintaining control over their lives, including the ability to choose a dignified death.

The disabilities of some individuals, such as the individual *Amici*, will never be life-threatening or reach a terminal phase. To these individuals, issues concerning assisted suicide are the same as those for anyone else, except that some have a greater physical need for assistance. Like people without disabilities, these *Amici* want the right to make this choice for themselves if they someday become terminally ill. They do not want to be deprived of this right simply because they have disabilities. Nor do they want their disabilities to be used by others to justify a wholesale denial of this right.

Other individuals have disabilities which are more likely to become life-threatening, such as the individuals with AIDS represented by the two *Amici* organizations. For these *Amici*, the issue of whether there is a right to obtain physician assistance in

hastening death has a more immediate and direct impact. *Amici* in this situation want to be able to retain autonomy in making decisions about whether or when to end irreversible suffering if their illness or disability enters a terminal phase.

All *Amici* have a significant interest in how this issue is resolved. While not all are certain whether they would ever decide to hasten their own deaths, all want the freedom of knowing that this option will be available if the worst were to occur. Further, they want the security of knowing that they can exercise this option safely, effectively and legally with professional assistance. *Amici* believe that this would be a uniquely personal, moral and religious decision, one that would primarily impact themselves and their loved ones – a decision that they should have the right to make for themselves without undue state interference.

In his personal statement, *Amicus* Evan A. Davis expresses concern that this Court may be misled by disability organizations claiming recognition of a right to die with the assistance of one's physician would harm people with disabilities. He points out:

The narrow issue before this Court is whether a terminally ill person whose death is inevitable and imminent has a right to die with dignity. Thus this case concerns only circumstances where life is already ebbing out and the natural process of death has already begun. In these circumstances I do not want myself or any others to be deprived of an ability to die with dignity because of arguments about the interests of people with disabilities that are not accurate or germane.

Personal statement of Evan A. Davis.

II. SUMMARY OF ARGUMENT

Like others in our society, people with disabilities wish to define their concept of existence, and to have autonomy over the uniquely personal decisions that effect their lives. Unlike most

other people, many of their basic rights have been denied until very recently. After having fought for their rights for so long, and having achieved recognition through enactment of the ADA as citizens fully capable of autonomy, they are offended that, on the basis of their disabilities, others are attempting to deny them and all other Americans the right to end their lives with dignity if they become terminally ill.

People with terminal illnesses have a liberty interest under the Fourteenth Amendment to end their lives with the assistance of their physicians, if they so choose. This liberty interest must be considered fundamental. It is at least as strong as other liberty interests recognized by this court, such as the right to terminate life support. Specifically, the current cases involve the right of an individual who is acutely aware of his or her suffering and impending death, and whose decision to hasten death by a few days or weeks does not harm the interests of any other person or potential person.

Assuming that the right is fundamental, the blanket prohibition in this case denying the right to all terminally ill individuals is not a narrowly tailored restriction necessary to achieve a compelling state interest. In fact, there is no compelling state interest in denying a person who is suffering and has little life left from ending his or her life with dignity. Any interests that the state has in denying the right are significantly outweighed by the interests of the individual. All legitimate state interests, such as ensuring competence, preventing coercion, and avoiding abuse, may be achieved through state regulation that does not unduly interfere with the basic right.

All objections raised by members of the disability community who oppose recognition of the right are either misplaced or may be addressed through appropriate regulation. Contrary to their assertions, neither the liberty interest in hastening death with physician assistance nor the diminished state interest in preventing this from occurring is in any way based upon quality of life considerations being imposed on the individual. It is derived from the autonomy of terminally ill

individuals to determine whether they wish to continue to live with their suffering for the brief remainder of their lives.

Moreover, any objections based on the Equal Protection Clause and the ADA lack merit. Terminally ill individuals are not similarly situated to people who are not terminally ill. They are dying, soon and often in great pain, and the right to end their suffering and control their deaths is a significant benefit to them. Giving them that respect does not deny them the protection of the state and does not discriminate against them in any way.

In contrast, as the Second Circuit found, competent, terminally ill individuals are similarly situated to people on life support who, when competent, indicated that they did not wish to live under those circumstances. Denying terminally ill individuals the right to assisted suicide violates the Equal Protection Clause.

In a compassionate society that respects the autonomy of people with disabilities, we must not deny people with terminal illnesses the right to end their suffering. For these individuals, physician assistance is the only means by which to ensure that their lives will end in a safe and humane manner.

III. ARGUMENT

A. PEOPLE WITH DISABILITIES ASSERT THAT PEOPLE WITH TERMINAL ILLNESSES HAVE A CONSTITUTIONAL RIGHT TO HASTEN INEVITABLE DEATH WITH THE ASSISTANCE OF THEIR PHYSICIANS

1. Competent, Terminally Ill Adults Have a Strong Liberty Interest Under the Fourteenth Amendment in Making End-of-Life Decisions Free of Undue Government Interference⁶

Because of the long struggle for recognition of their autonomy, the Fourteenth Amendment's Due Process limitations on the state's ability to intrude into the most important and personal matters of our lives has particular importance to people with disabilities. Amici agree with the Ninth Circuit that there is a liberty interest in determining the time and manner of one's death, and that "[c]ertainly, few decisions are more personal, intimate or important than the decision to end one's life, especially when the reason for doing so is to avoid excessive and protracted pain." *Compassion in Dying v. State of Washington*, 79 F.3d 790, 813 (9th Cir. 1996).

Amici further agree with the Ninth Circuit's application of *Planned Parenthood v. Casey*, 505 U.S. 833 (1992) (aff'g *Roe v. Wade*, 410 U.S. 113 (1973)) and *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990)). The right to "define one's own concept of existence," found in *Casey*, 505 U.S. at 851, and to

⁶ Although the Ninth Circuit decided this case on the basis of a Fourteenth Amendment liberty right, and this brief will focus on that right, Amici believe that there are additional bases for finding a right to assisted suicide. In particular, they contend that there is a strong privacy right in the Constitution for people with terminal illnesses to be protected from state intrusion. As Justice Brandeis stated in his famous dissent in *Olmstead v. United States*, 277 U.S. 438, 478 (1928), the framers of the Constitution "conferred, as against the government, the right to be left alone--the most comprehensive of rights, and the right most valued by Civilized men." In addition, at least one commentator has argued that a Fourteenth Amendment property right in one's body precludes state prohibition of assisted suicide. Roger F. Friedman, *It's My Body and I'll Die if I Want To: A Property-Based Argument in Support of Assisted Suicide*, 12 J. Contemp. Health L. & Pol'y 183 (1995).

have autonomy over the "uniquely personal decisions" that affect their lives, found in *Cruzan*, 497 U.S. at 281, are extremely important to people with disabilities. Where for generations, almost every aspect of their existence was defined by a paternalistic society that labeled them inferior and relegated them to institutions, they are unwilling to relinquish their autonomy.

This Court has previously found that a liberty interest is implicated when an individual is subject to state-imposed pain and suffering, even when such pain and suffering involves no more than a student being paddled for disciplinary purposes. *Ingraham v. Wright*, 430 U.S. 651, 674 (1977). In the current cases, the states are effectively forcing terminally ill individuals to incur severe pain and suffering. The state's interest in preventing the individual from escaping this anguish is minuscule.

The liberty interest asserted here is also no less compelling than that in *Cruzan*, where this Court recognized a competent individual's liberty right to refuse medical treatment and obtain active medical assistance in withdrawing existing treatment even when this will result in death. *Cruzan*, 497 U.S. at 261. Here, Respondents and *Amici* seek recognition of a right for terminally ill individuals to obtain medical assistance that will likewise cause death. While Nancy Cruzan could have lived for years unconscious on life support, the individuals in this case were fully conscious of their brief remaining life, their pain and suffering, and their desire to end their suffering.

2. The Second Circuit Implicitly Agreed With the Ninth Circuit That There is a Liberty Interest for People with Disabilities (and Other Individuals) With Terminal Illnesses in Hastening Their Own Death

Although the Second Circuit decided *Quill v. Vacco*, 80 F.3d 716 (2nd Cir. 1996), based on the Equal Protection Clause of the Fourteenth Amendment, it is clear from its language that there is a due process liberty interest in deciding when and how to die. *Quill*, 80 F.3d at 725. In discussing "the protection of minorities,

the poor, and the non-mentally handicapped," the court concluded that "[i]n point of fact, these persons themselves are entitled to hasten death by requesting [withdrawal of life support] and should be free to do so by requesting appropriate medication to terminate life during the final stages of terminal illness. *Quill*, 80 F.3d at 730 (emphasis added).

As one commentator concluded, "[t]he Second Circuit ...says that no such liberty interest exists, yet in effect bases its Equal Protection Clause analysis on the existence of just such an interest." Christopher N. Manning, *Live and Let Die? Physician-Assisted Suicide and the Right to Die*, 9 Harv. J.L. Tech 513, 515 (1996). Thus, while certiorari was granted in this case in part due to differences in the reasoning of the two Circuit courts, there seems to be greater agreement between the Circuits that there is a liberty right to assisted suicide than is apparent from the Second Circuit's holding.

3. The Liberty Interest Asserted Here Is Fundamental and May Not Be Impaired Without a Compelling State Interest

These cases are about the ability of a terminally ill individual to die with dignity; however, they are equally about whether we, as a society, believe that the state should be allowed to impose itself at the patient's deathbed, between the patient, family members and the physician, as an equal medical decision maker. They are about whether terminally ill individuals are accorded the respect they deserve in making what may be the most difficult decision of their lives, and whether the state may incarcerate their physicians for honoring their request.

Amici believe that the ability of the state to intrude in and interfere with the final wishes of a dying person is unacceptable in a free society. They contend that the decision of terminally ill individuals to select the time and manner of their deaths cannot be infringed upon by a state without a compelling state interest that is achieved through a narrowly-tailored restriction. *Reno v. Flores*, 507 U.S. 292, 301-02 (1993). *Amici* agree with Justice Stevens, who in his dissent in *Cruzan*, concluded "[c]hoices about

death touch the core of liberty. Our duty, and the concomitant freedom, to come to terms with the conditions of our own mortality are undoubtedly "so rooted in the traditions and conscience of our people as to be ranked as fundamental..."⁷ *Cruzan*, 497 U.S. at 343 (emphasis added).

4. There is No Compelling State Interest in Denying Terminally Ill Individuals the Right to Die, and the Liberty Interest of the Individual Substantially Outweighs Any State Interests

If this Court finds the interest being asserted here is fundamental, as *Amici* contend, any restriction on pursuing that interest must be narrowly tailored to further a compelling state interest. *Reno*, 507 U.S. at 301-02. The restrictions being considered are not narrowly tailored; they fully preclude individuals from obtaining the assistance of their physicians in hastening their death. Moreover, there is no compelling state interest that would justify the denial of the final wish of a suffering terminally ill individual to end his or her life with dignity.

If, on the other hand, this Court finds the interest asserted is only important, it must be balanced against other relevant state interests. *Cruzan*, 497 U.S. at 279; *Youngberg*, 457 U.S. at 321. After an exhaustive analysis of all relevant state interests, the Ninth Circuit found that the balance weighs heavily in favor of the individual. *Compassion in Dying*, 79 F.3d at 799. *Amici* agree with this analysis, and wish to add only that the interests of the state in protecting competent people with terminal illnesses (or people with other disabilities) is no greater than its interest in protecting other competent individuals.

⁷ Justice Stevens further found that "... not much may be said with confidence about death unless it is said from faith, and that alone is reason enough to protect the freedom to conform choices about death to individual conscience." *Id.* *Amici* strongly agree. See Statement of Amicus Evan Davis.

Amici recognize the legitimate interest of the state in protecting and preserving life. The interest in protecting life is best furthered by ensuring that the decision to end life with the assistance of a physician, is made voluntarily, by a competent, terminally ill individual. The state always has this interest and may pursue it through effective regulation.

However, the state's interest in *preserving* life diminishes, and the interest of the individual to be protected from state intrusion increases, as the potential for life diminishes. *In Re Quinlan*, 355 A.2d 647 (N.J. 1976), cert. denied sub nom 429 U.S. 922 (1976). *Garger v. New Jersey*, 429 U.S. 922 (1976). The interest of the terminally ill individual in ending his or her suffering far exceeds that of the state in preserving what little life remains.

While *Amici* recognize the legitimate interests of the state in protecting individuals from the actions of others, they and the majority of people with disabilities in this country do not want the protection of the state from their own actions and decisions.

5. The Legitimate State Interest in Protecting People with Terminal Illnesses or Other Disabilities from Abuses Can Be Protected Through State Regulation

The state has a legitimate interest in ensuring that all individuals who seek physician assisted suicide are competent adults who have made their decision voluntarily, without coercion or undue influence. In addition, the state may legitimately seek to ensure that the individual has had access to medical or psychological counseling and is fully aware of his or her options. See personal statement of Amicus Barbara Swartz.

A state may enact rules to protect state interests so long as they do not impose an undue burden "with the purpose or effect of placing a substantial obstacle in the path of" the ability to make the constitutionally protected decision. *Casey*, 505 U.S. at 877. In the context of physician assisted suicide, the state may not regulate with the purpose or effect of placing a substantial

obstacle in the path of a terminally ill individual to end his or her life with the assistance of a physician.

There are, however, clear measures a state might take to protect its legitimate interests. In particular, as long as it does not cross over the substantial-obstacle line, a state might impose the following safeguards:

- requiring the individual to repeat the request on more than one occasion;
- requiring the request to be made to more than one doctor;
- requiring the individual to be provided an opportunity to discuss the decision with a mental health professional;
- requiring the individual to be informed of programs and resources that are available to improve the quality of his or her remaining life; and
- requiring the individual to be informed on several occasions that he or she may, and is encouraged to, change his/her mind at any time.

These illustrate several of the requirements a state would be allowed to impose to protect its legitimate interest in ensuring competent, voluntary decisions and preventing coercion to choose hastened death. In addition, states may require hospitals, nursing homes, and other medical institutions to report on their compliance with these requirements.

Amici are committed to ensuring that the right of terminally ill individuals to obtain physician assistance in dying with dignity is not abused, that all individuals who choose to hasten their deaths do so freely, without pressure or coercion, and that they are aware of available options should they choose to continue to live. See personal statement of *Amicus* Susan Webb.

B. THE RIGHT TO ASSISTANCE IN DYING WILL BENEFIT PEOPLE WITH TERMINAL ILLNESSES, AND WILL NOT ADVERSELY AFFECT OTHER PEOPLE WITH DISABILITIES

1. Neither the Strong Liberty Interest in Hastening Death, Nor the Diminished State Interest in Interfering With This Decision, Are Based on Any Externally-Imposed Quality-of-Life Considerations

Some disability organizations that oppose the right to assisted suicide contend that the right is based on a social perception that people with terminal illnesses and other disabilities have a diminished quality of life. This contention is inaccurate. The strong liberty interest of terminally ill individuals in controlling the circumstances of their deaths, and the diminished state interest in interfering with this decision, are derived from their autonomy in making decisions about what little remains of their lives.

The interests do not derive in any way from any perceived diminished quality of life for individuals with disabilities or terminal illnesses. Quality of life is a subjective valuation belonging to the individual, not the courts or the states. Whether the quality of the life remaining for a terminally ill person is sufficient to justify whatever pain and suffering he or she may be enduring is a decision for that person, and that person alone.

2. The Right to Hasten Inevitable Death is a Benefit for People with Terminal illnesses That is Not Prohibited By Either the Equal Protection Clause or the Americans with Disabilities Act.

Some opponents of the right argue that it would deprive people with disabilities of the equal protection of the laws and would otherwise discriminate against them in violation of the ADA. These arguments are based on a fundamental

misunderstanding of the right. They characterize the benefit to terminally ill individuals of a right to hasten their own death as the discriminatory denial of a statutory right to be protected from their own decisions to end their lives. Regardless of this flip-flopped reasoning, the majority of people with disabilities regard the right to death with dignity as a benefit, not a legal detriment.

The Equal Protection Clause of the Fourteenth Amendment commands that no state shall "deny to any person within its jurisdiction the equal protection of the laws," which essentially means that all persons who are similarly situated should be treated alike.⁸ *City of Cleburne, Tex. v. Cleburne Living Center*, 473 U.S. 432, 439 (1985). The threshold question is whether people with terminal illnesses are similarly situated to non-terminal individuals with respect to their interest in dying. The answer is clearly no. Terminally ill individuals who are at the end of their lives, often with severe pain and suffering, have a different interest in end-of-life decisions than others.

⁸ It is currently not clear what standard of review should apply to legislative classifications based on disability for purposes of equal protection analysis. On the one hand, the Supreme Court clearly found that people with mental retardation (perhaps the most vulnerable group in the disability community) are not entitled to heightened scrutiny. *Cleburne*, 473 U.S. at 422. On the other hand, *Cleburne* was decided in 1985, prior to the Congressional finding in the enactment of the ADA that "individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society based on characteristics that are beyond the control of such individuals . . ." 42 U.S.C. § 12101(a)(7). Based on this finding, this Court may find that legislative classifications based on disability must receive the highest level of scrutiny. Cf. *Trautz v. Weisman*, 819 F. Supp. 282 (S.D.N.Y. 1993). Whichever standard this Court decides to apply, the right of terminally ill individuals to end their lives does not violate the Equal Protection Clause for reasons discussed herein.

Moreover, given the nature of the right at issue here, it is more appropriately viewed as an interest held by all individuals that may be exercised as a right if and when they become terminally ill, rather than a right held by terminally ill individuals and not others. Terminal illness, like disability generally, does not discriminate; it may affect anyone. Denying people who are not terminally ill the right to end their lives with physician assistance, until such time that they become terminally ill, does not deny them equal protection.

The second question is whether the right to assisted suicide deprives people with terminal illnesses of a benefit that is available to other individuals. Again, the answer is no. The right being asserted here would give terminally ill individuals an additional choice that they currently do not have. It would not require them in any way to exercise that choice. It would not deprive them of life. It would not deprive them of protection from murder. It would not deprive them of state suicide prevention services. In fact, it would not deprive them of anything.

The ADA prohibits actions by or policies of public entities that "exclude from participation in" or "deny the benefits of" any program, service, or activity of a public entity or by which persons are "subjected to discrimination by any such entity." 42 U.S.C. § 12132. Again, the right being asserted does not deny any benefit to any person with a disability, nor does it exclude any person with a disability from participation in any state program, service or activity.⁹ The ADA was not intended to

⁹ The one way in which the ADA may be applicable, however, is with respect to individuals with terminal illnesses who are not capable of self-administration of the lethal drug. Certain people with disabilities, such as some people with quadriplegia, have physical limitations which severely restrict or render impossible the ability to self-administer drugs. Modern technology has resolved this issue for the vast majority of these individuals through the development of assistive devices that allow them to self-administer. However, to the extent that

prevent people with disabilities from having greater options than other people, particularly when they are entirely free not to exercise those options.

Moreover, the ADA was not intended to protect people with disabilities from their own decisions. One form of discrimination against people with disabilities explicitly mentioned as a basis for the ADA is "overprotective rules and policies." 42 U.S.C. § 12101(5). Terminally ill individuals have a particularly strong liberty interest in not being "protected" by the state from their own end of life decisions. The right to obtain physician assistance to hasten their death is a significant benefit to them. They do not want protection from this choice.

3. The Standard of Terminal Illness Will Allow States to Prevent People Who Are Not Terminally Ill from Ending Their Lives With Physician Assistance

Some disability organizations that oppose assisted suicide contend that this right inevitably will be expanded to people with disabilities who do not have terminal illnesses. There is no reason this will occur. The requirement that the individual seeking to end his or her life must have a terminal illness that makes death imminent and inevitable is readily capable of definition and implementation. Many states and model codes define the term "terminal illness." Brief of Respondents (*Glucksberg*) at 32.

The fact that there is no uniform definition for "terminal illness" is of little consequence. At this stage, we need only consider the broad parameters of the right. In the current cases,

9(...continued)

some of these individuals who are terminally ill are incapable of self-administration even with an assistive device, the ADA would probably require that the individual be permitted the assistance of his or her physician in administering the drug. Such administration would be entirely consistent with the active role that physicians currently play in conducting abortions and in terminating life support systems.

all people with terminal illnesses are precluded from obtaining the assistance of their physicians in ending their lives. This blanket prohibition clearly violates the liberty rights of many individuals who are, without any doubt, terminally ill. As long as a state defines terminal illness within the bounds of reasonableness, it may prevent people who fall outside those bounds from obtaining assistance in dying.

Some opponents point to the Netherlands as proof that the right to physician assisted suicide cannot be contained to people with terminal illnesses. Any such comparison is misleading. In the Netherlands, physician-assisted suicide is not allowed by statute, but physicians who adhere to official guidelines will not be prosecuted for assisting patients who request assistance in dying. However, those guidelines have never required that the patient be terminally ill or that the patient's suffering be physical. Chris Docker, *Euthanasia in Holland*, ¶ 1 (1996) <<http://www.euthanasia.org/dutch.html>> .

Two recent studies of doctor-assisted death in the Netherlands suggested that tolerance of the practice has not produced the "slippery slope" leading to abuses which critics have predicted. P.J. van der Mass, et al., *Euthanasia, Physician-Assisted Suicide and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995*, 335 N. Eng. J. Med. 1699 (Nov. 28, 1996); G. Van Der Wal et al., *Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands*, 335 N. Eng. J. Med. 1706 (Nov. 28, 1996); M. Angel, *Euthanasia in the Netherlands – Good News? Or Bad?*, 335 N. Eng. J. Med. 1676 (Nov. 28, 1996).

The situation in the Netherlands, therefore, provides no support for the proposition that the right limited to terminally ill individuals in our country will necessarily be expanded.

4. The Standard of Voluntariness Will Allow States to Ensure Only Competent Individuals Who Choose to Hasten Death With Assistance Are Allowed to Do So

Opponents of the right to die further assert that people with disabilities will be induced to end their lives by others who consider them inferior or a burden. However, the right asserted here is based entirely on the voluntary choice of a competent individual with a terminal illness to end his or her life. As discussed above, the state is free to enact regulations to ensure that the decision is made voluntarily by a competent adult who was not subject to coercion or undue influence. Despite such standards, opponents contend that this right will be extended to incompetent individuals. They base this conclusion on case law concerning the right to refuse life-sustaining medical interventions. However, such expansion is by no means inevitable and may be precluded by this Court's decision.

The liberty right to assisted suicide is different from the right to withdraw life support. While competent individuals in both situations are similarly situated for purposes of equal protection analysis, the right to withdraw life support is based fundamentally on the common law right to be free from bodily invasions. *Cruzan*, U.S. at 269. The courts have appropriately found that, like competent individuals on life support, incompetent individuals have a right to be free from such invasions. The right to assistance in dying is based on the interest of the terminally ill individual to control his or her life. Because the right is based on the autonomy of the individual, it may be limited to those individuals who are capable of autonomy-competent adults.

5. In the United States, the Right of Terminally Ill Individuals to Choose Assisted Suicide Will Never Be Converted into a Right of the State to Authorize the Murder of People with Disabilities

Some organizations that oppose physician assisted suicide for competent patients who are dying and suffering contend that this is the first step toward a society in which life is devalued and people with disabilities are routinely killed by their doctors. These groups point to the "euthanasia" program authorized by

Nazi Germany in the 1930s as a graphic example. There are several serious problems with this analogy.

First, our country is not Nazi Germany; ours is a nation dedicated to individual freedom in which the state is constitutionally limited in depriving individuals of life, liberty or property and the press is constitutionally empowered to inform the citizenry of abuses of state power. The notion that the state will have an interest in killing, or authorizing the killing of, people with disabilities is ludicrous. One could just imagine the TV coverage of such abuses on the evening news, or "60 Minutes", as well as the criminal and civil legal actions that would inevitably follow.

Second, the Nazi program did not begin by granting a right to assisted suicide for people with terminal illnesses. It began with a determination by the state that people with disabilities are inferior, have an inferior quality of life, and are therefore disposable. That determination was in fact entirely consistent with the goals and ideals of the Nazi party, and flourished when the party flourished. By contrast, the notion that people with disabilities may be killed without their consent is, and will always be, abhorrent to the American public. The false notion that they are inferior or necessarily have an inferior quality of life may never in this country serve as a basis for any public policy, particularly a policy that would deprive them of life, liberty or property. The right being sought here is not in any way based on any perceived inferiority, or inferior quality of life of, people with terminal illnesses.

Third, and most important, the state in Nazi Germany gave the medical profession unbridled power and authority to control the lives and deaths of individuals with disabilities. In current cases, Respondents and *Amici* seek to expand individual autonomy and liberty, and to diminish the power and authority of the state to make or authorize decisions concerning the life and death of an individual. The implication of recognition of a right to assisted suicide is, therefore, not that the state will have more

power to take the life of any of its citizens, with or without disabilities, but rather that it will have less power.

Amicus Hugh Gallagher, author of *By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich*, and one of the world's foremost experts on the Nazi euthanasia program, describes in his personal statement how the medical establishment in Germany, at its request, was authorized by the government to provide a "mercy" death for patients who in the judgment of their physicians had "lives not worth living," and that the patients were given no choice over whether to live or die. In indicating his support of the right to assisted suicide, he concludes that:

The Nazi's euthanasia program offers a horrible example of how easy it is to go wrong when the state or a group authorized by the state is allowed to assume the power to judge the worth of another. Ironically, this program is now being used by some as a justification to deny Americans in the terminal stage of illness the right to die with assistance. In fact, the German experience shows how important it is that the autonomy of people with disabilities be honored in all aspects of their lives. . . .

The case of assisted suicide is quite different: the patient with a terminal illness retains complete choice over whether to live or to die. Neither the state nor the physician may decide, based on their conceptions of the individual's quality of life; the individual must assess his or her own quality of life. This is true whether or not the individual has a disability....

To my mind, the issue comes down to control – control over one's Self. This control over Self is the very heart of the disability rights struggle. In Nazi Germany 60 years ago, people with disabilities were deprived of all control over their Selves. They were killed not because they sought death but because they did not measure up to "quality of life" standards set

by their physicians with the concurrence of the state. This must never happen here.

Personal statement of Hugh Gregory Gallagher.

C. DENIAL OF THE RIGHT TO ASSISTANCE IN DYING WOULD DENY PEOPLE WITH TERMINAL ILLNESSES THE EQUAL PROTECTION OF THE LAWS

While the people with terminal illnesses in these cases are not similarly situated to people who are not terminally ill for purposes of the Equal Protection Clause, they are similarly situated to competent people on life support who have clearly indicated that they do not wish to live under such circumstances. *Amici* agree with the decision of the Second Circuit that "New York does not treat similarly circumstanced persons alike: those in the final stages of terminal illness who are on life-support systems are allowed to hasten their deaths by directing the removal of such systems; but those who are similarly situated, except for the previous attachment of life-sustaining equipment, are not allowed to hasten death by self-administering prescribed drugs." *Quill*, 80 F.3d at 729. See, personal statement of *Amicus* Barbara Swartz.

D. A COMPASSIONATE SOCIETY THAT RESPECTS PEOPLE WITH DISABILITIES MUST NOT DENY TERMINALLY ILL INDIVIDUALS THE RIGHT TO END THEIR SUFFERING WITH ASSISTANCE

People with terminal illnesses have an immediate and urgent liberty interest in the right to hasten their death with the assistance of their physicians, whether or not they decide to exercise that right. Diseases such as cancer and AIDS may cause great pain and suffering, physical deterioration, and mental anguish. A society that cares about these individuals and that respects their autonomy must not deny them the opportunity to shorten the period of their suffering and to die with dignity in a safe and effective manner, with the assistance of their physicians.

1. The Decision of a Competent, Terminally Ill Individual to End His or Her Life Must Be Assumed to Be Rational and Should Be Respected

In our legal system, the decisions of competent individuals are presumed to be rational.¹⁰ This presumption applies to the decisions of people with disabilities, and any contrary assumption by a state in establishing its policy would violate the ADA and our national policy concerning people with disabilities. Therefore, a state may not assume that the decision of a competent terminally ill individual to end his or her life is irrational and may not base a policy precluding assisted suicide on such an assumption.

Yet, some disability rights advocates who oppose the right to die seem to argue that people with disabilities are not capable of autonomy for purposes of determining when and how they should die when facing death with a terminal illness. The reason for this apparent inconsistency with their basic philosophy is that, they contend, many people with disabilities have so few resources or viable options that they cannot make a rational choice to end their lives. This inconsistency is unacceptable to *Amici* and the majority of people with disabilities.

Amici are leaders in the disability community who are committed to improving the lives of all people with disabilities and to enhancing the options available to them. They agree that our society often does not provide the support necessary for people with disabilities to live independently in their communities. However, the fact that the circumstances of the disabled population are, as a whole, far less than ideal in this country, and are likely never to be perfect, is no justification for depriving those who have a terminal illness of the right to end their suffering. These individuals are entirely capable of making rational decisions. See personal statement of Susan Webb.

¹⁰ See, *H.L. v. Matheson*, 450 U.S. 398, 453 (1951); *Davis v. United States*, 160 U.S. 469, 477 (1895).

As indicated above, between 66 and 90 percent of people with AIDS support the right to assisted suicide. Significantly, the study that found that more than half (55 percent) have considered this option for themselves, also found that the strongest predictor of interest in physician assisted suicide was having witnessed terminal illness in a family member or friend. Breithart, *supra* at 242; Tindall, *supra* at 1069. This suggests that these individuals know from personal experience the pain and suffering a terminal illness can impose, and have concluded that a person should have the right to end that agony if they so choose. According to one observer:

Patients who are dying of cancer and wish to lessen their suffering raise the concept of rational suicide. They are competent to make decisions, feel that they have completed their contribution to the world, and are unlikely to contribute anything more in the few weeks remaining. The disease is advanced and advancing, and they understand and accept it. Estimates of survival are in weeks rather than months, and they are quite willing to relinquish the possibility of another remission. They do not believe in miracles. Indeed, their condition may be so pitiful as to command the sympathy of family, friends and caregivers alike. The only desire is to shorten the process of dying and terminate the suffering.

Charles F. McKhann, *Is There a Role for Physician-Assisted Suicide in Cancer? Yes*, Important Advances in Oncology, 267, 269 (1996).

2. Recognition of the Right to Receive Physician Assistance Will Serve to Ensure Safety and Curtail Abuse

As was true with abortion in the years before this Court's decision in *Roe v. Wade*, the continued criminalization of physician assisted suicide has not stopped many physicians from aiding competent patients to end their suffering. See Jody B. Gabel, *Release From Terminal Suffering? The Impact of AIDS on*

Medically Assisted Suicide Legislation, 22 Fla. St. U.L. Rev. 369, 372-73 (1994); L. Slome, J. Moulton, C. Huffine et al., Physicians' attitudes toward assisted suicide in AIDS, 5 J. AIDS 712-18 (1992); Dick Lehr, *Death & the Doctor's Hand, Increasingly, Secretly, Physicians Are Helping the Incurably Ill to Die*, Boston Globe, Apr. 25, 1993 at 1.

In the face of legal prohibitions on physician assistance, others are coming to the aid of the dying. One recent study surveyed 1139 critical care nurses in the United States, of which 71 percent practiced exclusively in intensive care units for adults. Of that group, 17 percent reported requests from patients or family members for euthanasia or assistance in suicide;¹¹ 16 percent of those asked, did so. An additional 4 percent stated they had hastened a terminally ill patient's death by pretending to provide life-sustaining treatment ordered by a physician. David Asch, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 334 N. Eng. J. Med. 1374-79 (May 23, 1996).

One California study of persons caring for loved ones with AIDS found more than 10 percent of these caregivers reported giving drugs to hasten their loved ones' death. M. Coode, L. Gourlay, L. Collette et al., *Dying of AIDS: The Role of Caregivers in Terminal Care and Hastened Death*, Center for AIDS Prevention Studies, University of California, San Francisco, Paper presented at the 10th International Conference on AIDS, Yokohama, Japan, August, 1994.

The ban on assisted suicide has simply ensured that persons lacking the requisite training will continue to intervene on behalf of those wishing to die. A desperate individual left to his or her own devices may likewise be forced to resort to whatever means are available to curtail suffering, such as "hanging, suffocation or shooting." Jeremy A. Sitcoff, *Death with Dignity: AIDS and a Call for Legislation Securing the Right to Assisted Suicide*, 29 J.

Marshall L. Rev. 677, 687 (1996). Without physician assistance, the consequences may be other than intended, potentially resulting in severe injury (e.g., coma, brain damage or increased agony). "Often, the person who has made a rational choice to die with dignity must accept his death in a totally undignified manner". *Id.*

3. People with Terminal Illnesses Should Not Be Compelled to Die in a Drug-Induced Semi-Conscious Haze

The typical treatment of people with terminal illnesses that cause great pain is to administer high levels of pain medication to the individual, which typically puts him or her in a semi-conscious state for an extended period of time. In administering this medication, the physician is fully aware that there is a significant probability of killing the patient. However, this is considered sound medical practice, while assisting an individual with the intent to help the individual end his or her life is a criminal act.

Individuals should not be forced to spend their final days in a drug-induced stupor to alleviate their pain. To many individuals, the prospect of leaving this world in such a state of prolonged semi-consciousness is a fate worse than death. In one study of eighteen patients with cancer, one patient with prostate cancer and bone metastases stated: "Who wants to suffer this kind of pain? The medication puts me to sleep. As soon as I wake up, there is the pain. If I can't live free of pain, I'm not living at all, simply existing." McKhann, *supra* at 268.

With the option of physician assisted suicide, terminally ill individuals may choose to remain fully conscious, recognizing that they may end their suffering permanently at any time. This option, therefore, allows them to spend their remaining days saying good-bye to their friends and relatives and putting their affairs in order. To them, and to most people, this dignified exit is far preferable to having their loved ones look on hopelessly as they slowly drift from drug-induced semi-consciousness to death.

¹¹ David A. Asch, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 334 N. Eng. J. Med. 1374-75 (1996).

4. Physician Assisted Suicide Allows People with Terminal Illnesses to Postpone Ending Their Lives Until a Later Phase of Their Illness

The recognition by people with terminal illnesses that they can end their suffering often gives them the will to continue to live. A strategy of many terminally ill individuals is to determine the point in the disease process when it would be unbearable to live and to decide to end their lives at that point. The control that this gives them over their lives often allows them to sustain a willingness to live. Many times, individuals reach the planned point and extend their self-imposed limit to a later stage of the disease. Often, they postpone the decision permanently, and die from the disease. Mary Evangelisto, *Death with Dignity: End-of-Life Issues for the HIV/AIDS Patient*, 34 J. Psychosoc. Nurs. 45, 46 (1996).

IV. CONCLUSIONS

Issues of autonomy and self-determination are at the heart of the struggle of people living with disabilities. They want to be able to control the decisions that affect their lives. Like the majority of Americans, they particularly do not want the state to deprive them of such control during their final days, if they have decided their suffering is intolerable. This decision must be made by the individual in consultation with his or her loved ones and personal physician. The state has no legitimate place interfering in this profoundly personal decision making process.

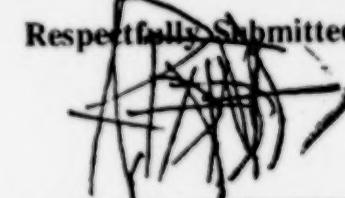
The right of terminally ill individuals to control their deaths is fundamental. There are few, if any, interests that are more basic to individual liberty, and few, if any, circumstances in which the state's interest is less. *Amici* do not want to be deprived of this right by the state simply because others, including others with disabilities, may not make this choice for themselves or because of concern over potential abuse. They do not want their disabilities to be used to justify the denial of this right to others. The interests of a dying person to control the remainder of his or her life far outweighs any state interests.

There is certainly no state interest sufficient to prohibit all people with terminal illnesses from obtaining compassionate assistance in dying from their physician.

Amici are committed to ensuring that the right to physician assisted suicide is applied fairly and appropriately. They believe that the vast majority of individuals who have available the option of physician assisted suicide will choose to live, comforted by the knowledge that the decision to continue to live is theirs and theirs alone. The enormous interest in this case by members of the disability community ensures that multitudes of disability rights advocates, including *Amici*, as well as other concerned individuals, will do everything they can to ensure this right is not abused and to encourage terminally ill individuals to choose to live.

The decision of the Ninth Circuit that people with terminal illnesses have a liberty right in ending their lives with the assistance of their physicians, and the decision of the Second Circuit that denial of this right constitutes a denial of the equal protection of the law, should be affirmed.

Respectfully Submitted,

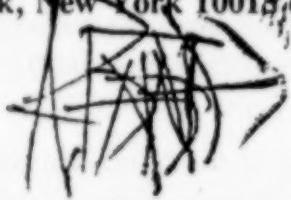


Andrew I. Batavia,
Bryan R. Cleveland
Marina L. Fontani
Susan F. Dournaux
McDERMOTT, WILL & EMERY
2200 Miami Center
201 South Biscayne Boulevard
Miami, Florida 33131
Telephone: (305) 358-3500

**Counsel of Record*

CERTIFICATE OF SERVICE

I HEREBY CERTIFY that true and correct copies of the foregoing were sent via U.S. mail to: William L. Williams, Deputy Senior Assistant Attorney General, Transportation and Public Construction Division, Office of the Attorney General, 905 Plum Street, Olympia, Washington 98504-0113; Barbara Billett, Solicitor General State of New York, Office of the Attorney General, The Capitol, Albany, New York 12224; and Marc F. Scholl, Assistant District Attorney, Appeals Bureau, One Hogan Place – Room 812, New York, New York 10013, on December 9, 1996.



Andrew I. Batavia

APPENDIX

**PERSONAL STATEMENTS
OF
AMICI CURIAE**

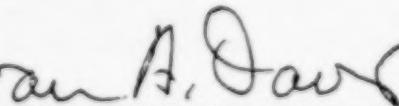
Personal Statement of Evan A. Davis

I am an attorney admitted to practice in the State of New York and a member of the Bar of this Court. I am a litigation partner with Cleary, Gottlieb, Steen and Hamilton in New York City. In 1949, at the age of five, I contracted polio and since then have gotten around with the help of braces, crutches and a wheelchair. For the last twenty years or so I have used the wheelchair almost exclusively. Because I received an excellent education and because my credentials are strong, this disability has not limited my practice.

I was asked to participate in this amicus brief by Professor Sylvia Law of New York University Law School. She told me that various groups representing persons with disabilities were filing amicus briefs in support of Petitioners urging that the interests of disabled people would be disserved by affirmance of the decisions below. As it happened I had just spent a good deal of time studying the legal issues now before this Court. With my knowledge of these issues in mind I agreed to participate because I thought the Court needed to be informed that if the issue before it is viewed narrowly, as it should be, affirmance would work absolutely no harm to the interests of people with disabilities.

My interest in this Court not being misled is two fold. The narrow issue before this Court is whether a terminally ill person whose death is inevitable and imminent has a right to die with dignity. Thus this case concerns only circumstances where life is already ebbing out and the natural process of death has already begun. In these circumstances I do not want myself or any others to be deprived of an ability to die with dignity because of arguments about the interests of people with disabilities that are not accurate or germane.

I also have an interest in this Court not being mislead because I believe it is uniquely the obligation of this Court under the Fourteenth Amendment to decide what is the proper scope of the citizen's right to be left alone by government in regard to seeking a dignified death. If this issue is left to the legislative process the result will likely be influenced by religious views whose sincerity I respect but which are contrary to my sincerely held religious views. Therefore I have a particularly strong interest in this Court making a sound decision on solely secular grounds based on accurate information.



Evan A. Davis

12/2/96

Date

Personal Statement of Hugh Gregory Gallagher

I am a writer and a historian. I am also a polio quadriplegic as a result of an attack of polio in 1952. For more than a decade, I have been studying and writing extensively on disability rights issues. I am particularly interested in the treatment that people with disabilities receive from the medical system. I am considered one of the foremost experts on the program authorized by Nazi Germany to "euthanize" over 200,000 of its citizens with disabilities.

The Nazi's euthanasia program offers a horrible example of how easy it is to go wrong when the state or a group authorized by the state is allowed to assume the power to judge the worth of another. Ironically, this program is now being used by some as a justification to deny Americans in the terminal stage of illness the right to die with assistance. In fact, the German experience shows how important it is that the autonomy of people with disabilities be honored in all aspects of their lives. I do not believe that people with terminal illnesses should be denied the option of ending their lives in order to obtain relief from intolerable pain and suffering. This most personal of all decisions should rest between the person and his God.

In my book, By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich, I describe in detail how the medical establishment in Germany, at its request, was authorized by the government to provide a "mercy" death for patients who in the judgment of their physicians had "lives not worth living." The program was authorized by Hitler in 1939 and placed under the direction of his personal physician. Although the program was called "euthanasia," the vast majority of the people killed were not terminally ill or in great pain or even requesting death. The killings began slowly, but soon enough, entire wards were being provided "final medical treatment." The patients were given no choice over whether to live or die.

The case of assisted suicide is quite different: the patient with a terminal illness retains complete choice over whether to live or to die. Neither the state nor the physician may decide, based on their conceptions of the individual's quality of life; the individual must assess his or her own quality of life. This is true whether or not the individual has a disability.

In our generation, great strides have been made to welcome people with disabilities into society as equal members with equal rights. For the first time, people with disabilities have assumed control over their own lives, without fear of sterilization, internment, segregation and ostracism, and the denial to their rights to vote, hold property, enter legal contracts, and obtain public education, transportation and accommodation. Now they should no more be denied the right to obtain assistance in dying if they become terminally ill than should anyone else.

Statement of Hugh Gregory Gallagher
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To my mind, the issue comes down to control -- control over one's Self. This control over Self is the very heart of the disability rights struggle. In Nazi Germany 60 years ago, people with disabilities were deprived of all control over their Selves. They were killed not because they sought death but because they did not measure up to "quality of life" standards set by their physicians with the concurrence of the state. This must never happen here.

In the United States today, we are debating whether an individual in the terminal stages of an illness should retain control over his/her Self and his/her personal concept of quality of life -- even to the point of death with dignity -- or whether such control should be circumscribed by the state.

In my own experience, it was this sense of control and the concomitant knowledge that I could end my life should the situation become unbearable, that kept me going through the extraordinary pain and suffering that accompanies acute polio. I will not turn over this control, or my personal decision to live or die, to the state. That decision is mine and mine alone.



Hugh Gregory Gallagher

Nov 28 1996

Date

Personal Statement of Barbara Swartz, Esq., In Support of Physician-Assisted Suicide

I have end-stage renal disease (ESRD) and have been considered legally disabled for the past twelve years. For eleven and a half years, I was a home hemo dialysis patient; six months ago, I had a successful kidney transplant. But I am more than a kidney patient. Professionally, I am a lawyer, a law professor and a lecturer in public health. During these past twelve years, I have been very active as a volunteer in my national kidney organization.

Throughout my career, I have been a fighter for and protector of human rights. I have worked for prisoners' rights, women's rights and patients' rights. A common theme running through these various areas is my strong commitment to the right of the individual to maintain her autonomy and dignity. In the area of patients' rights, I believe in the full and active participation of patients in our own health care decisions including end of life and death decisions. It is in making these profoundly difficult decisions that the right to individual autonomy becomes most meaningful. Competent patients already have the legal right to refuse treatment even if this decision leads to their death. In my mind, there is little legal difference between this right for a physician to help a person die with dignity, and the opportunity for a physician to prescribe medication which a competent person may choose to self-administer even though it too may lead to her death. In both cases, we are discussing the means used, either passive or proactive, to achieve the same end result. As a competent patient, I believe passionately in my right to maximum participation in one of the most intimate decisions that affects me: how I die.

I do not say that this is an uncomplicated issue and I understand that honorable people may disagree on what approach to take in cases of people wishing to die when they are in the end stages of a terminal illness. Before a physician consents to a patient's request for a lethal dose of medication, I would want to ensure that a patient is offered effective pain management and appropriate psychological assistance. Ideally, I would also like to believe that there has been an active and ongoing dialogue between the physician and the patient about this decision. But this is a matter of effective regulation rather than a strict prohibition of the practice. Ultimately, I believe that the final decision about whether to live or die must be left to the patient.

I have always been actively involved in decision making about my illness. From the onset of my kidney disease, I had to make the decision about whether to go on dialysis or not. I knew that a decision not to choose dialysis was a

STATEMENT OF MICHAEL A. STEIN

decision to die. Every time I dialyzed, I made the decision to choose life over death. I also had to decide whether to put myself on the transplant list and then when a kidney was offered to me, whether to accept the offer. Each of these decisions is more comparable to a competent person's right to refuse treatment. However, I would hope that if I chose to end my life because of unbearable pain and suffering, and I needed help, I would be able to call upon my physician to assist me in dying with dignity. For me, the basic question is whose life and death is it anyway?

Barbara Swartz, Esq.
Barbara Swartz, Esq.

November 30, 1996

I am a thirty-three year old individual who uses a wheelchair due to a childhood illness that brought about spastic paraparesis. Aside from this limitation on my mobility, I am otherwise in good physical condition and enjoy an active and healthy lifestyle.

Professionally, I teach a course on Physical Disability Law at New York University Law School while working towards completion of my Ph.D. studies in legal history at Cambridge University. Thereafter, I will return to full time law teaching and advocacy for the rights of individuals with disabilities.

In the past, I have tried to advance the status of disabled people through the publication of law review articles (See, e.g., Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of People With Disabilities, 60 Brooklyn L. Rev. 1069 (1994); From Crippled to Disabled: The Legal Empowerment of Americans With Disabilities, 43 Emory L.J. 247 (1994)), editorials (See, e.g., Attitudinal Barriers to Hiring Attorneys with Disabilities, 17 Physical and Mental Disability L. Rev. 214 (1993); When Justice is Blind: Appointing Vision-Impaired Individuals to the Bench, 1 Minority L.J. 5 (1992)), service as President of the National Disabled Bar Association (1992-94), and direct lobbying of members of the United States Congress.

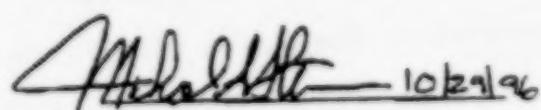
On a personal note, I am newly wed to a wonderful person who makes me enormously happy. In other words, I have every reason to be grateful for my existence and to want its indefinite continuation.

Personal Statement of Susan Webb

Nevertheless, I feel so strongly about allowing people with disabilities the option of assisted suicide, that I readily agreed to be named as party in this amicus brief. This is because, whether through illness or other circumstances, occasions arise that make some peoples' lives unbearably painful. Without the option of a facilitated passing, their existence becomes no more than an extended personal torture as they are sentenced to wait for a grim and demeaning demise. By honoring an opportunity of assistance, those people who so choose, may regain control of both their existence and their dignity.

I believe that whether an individual chooses to bring about her own demise is an intimately personal choice and should remain a private decision, protected from state regulation. The blanket prohibition against assistance in the statute at bar is invasive, eradicating a difficult decision which must be made by an individual in consultation with his conscience, family and friends.

The option of assisted suicide should be available for people who currently desire this course as well as for others, such as myself, who want a similar freedom to act in case of future circumstances.



Michael A. Stein

This statement declares my personal support of a terminally ill individual's right to die. I also support a terminally ill individual's right to die with assistance of another when it is assured that the individual has made his/her decision in writing and has made the decision after as many options for living as practicable have been made available to him/her. Under no circumstances must an individual be assisted in his/her suicide under coercion, especially by the individual who will be assisting.

Like many other persons with a disability, I have some concerns about this issue. Many persons with disabilities are relegated to institutions such as nursing homes where they feel trapped and without other options based on archaic, paternalistic systems. The only information they are given is often from persons who are not themselves disabled and who cannot fully understand the disability experience firsthand and that life with a disability can be full and rewarding.

As a disability advocate I am personally committed to working on legislation, regulations, etc. that would guarantee that individuals with disabilities have access to resources and information that might lead them to choose life instead of death. I am committed to ensuring that no one chooses death because he or she does not have adequate information with which to make an informed choice. However, once a terminally ill individual has allowed considerable time and thought, with a complete understanding of their options, the decision to end his/her life with or without assistance must be respected and implemented.

I am a person who has lived with a significant disability since 1974. As a disability advocate, executive director of an independent living center, elected board member of a national disability-rights organization and compassionate American, I make this statement from a recognized position of expertise and after much forethought. However, this statement is to be construed as a personal declaration and in no way reflects the opinions of any organization to which I belong.



Susan Webb

Date

12-3-96